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ABSTRACT

This paper offers a perspective on people learning to build community, across the imposed social barriers that separate people with substantial disabilities from other people. The paper presents the story of a woman who was able to move from an institutional setting to her own home because of the community-building carried out by her support circle. Such community-building involves negotiating entry into new settings and new roles, usually as the first person with a substantial disability to do so; arranging adequate systems of personal assistance; acquiring appropriate technical aids and devices; and finding adequate funding. Five types of person to person commitments which people involved in community building have found useful in understanding and extending their efforts are discussed. These include: (1) anchoring the individual who has a disability, (2) allying with the person to make meaningful change, (3) providing assistance in dealing with the effects of disability, (4) forming associations of groups of people created to further their interests, and (5) organizing political action to ensure just and effective public policies. People who share these five commitments and nurture them are likely to create new ways to build and be a community. (Contains 10 references.) (JDD)

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UNFOLDING CAPACITY: PEOPLE WITH DISABILITIES AND THEIR ALLIES BUILDING BETTER COMMUNITIES TOGETHER

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Unfolding Capacity

People With Disabilities and Their Allies Building Better Communities Together

John O'Brien and Connie Lyle O'Brien*

> *The basis of people's lives with one another is twofold, and it is one -the wish of each person to be confirmed as what each person is, even as what that person can become; and the innate capacity in each person to confirm others in this way. That this capacity lies so immeasurably fallow constitutes the real weakness and questionableness of the human race; actual humanity exists only where this capacity unfolds.*
>
> *-Martin Buber*

Three kinds of change, occurring at different scales, shape the opportunities for people with substantial disabilities** to participate in unfolding the capacity for mutual confirmation which Buber finds at the root of our common life. Declarations of social policy, such as the Canadian Constitution's Charter of Rights and Freedoms and the Americans with Disabilities Act, reflect a new awareness of the rights (and political influence) of people with disabilities and their families by forbidding discrimination on the basis of disability. Services to people with substatial disabilities gradually shift attention and investment away from congregate services. So small but growing and visible numbers of people with substantial disabilities live in ordinary housing, have support for ordinary employment, and attend ordinary schools. At the smallest scale are the efforts that concern this paper. This kind of change involves people learning together how to build community across the imposed social barriers that separate people with substantial disabilities from other people.

Each of these changes serves as a platform for further change by revealing how much more must be done before people with substantial disabilities take their rightful place as citizens. Even where they are in force, declarations of rights serve

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** In referring to "people with substantial disabilities", we follow current usage among advocates for personal assistance services in the US. Substantial disability is defined by the requirement for significant amounts of assistance in performing everyday tasks and participating in everyday life, not by a disability category.

as much to expose contradictions with other policies, and conflicts with other political interests, as they do to stimulate habitual regard for the dignity of people with disabilities. The successes of people with substantial disabilities in living, working, and learning in ordinary places increase dissatisfaction at the contrast between their situation and the far less satisfactory conditions still imposed on many people who remain segregated and controlled by the service programs they rely on. These successes also yield disappointment because establishing people in typical settings seldom proves sufficient to support full and valued lives. More and more people who have worked hard for service reform nod a bit sadly when someone observes that people with disabilities are in communities without yet belonging to communities. Work to build community remains very small in scope, with many more people debating it than people working to learn how to do it.

A perspective on community building

This paper offers a perspective on efforts to build community. In general terms, we can define community building as the intentional creation of relationships and social structures, that extend the possibilities for shared identity and common action among people, outside usual patterns of economic and administrative interaction. We are especially interested when this work involves people with substantial disabilities.

In particular, this chapter presents some of what we have learned by listening to the stories of people who have made important changes in their lives by working together. Our method for learning is simple: we locate people with substantial disabilities who have been involved in an important change, ask involved people to tell us their stories of how the change happened, invite their reflections on what was most important in making the change, look for common images and themes across stories of change, re-read the stories through different theoretical lenses, and, finally, re-tell the story and ask the original story tellers to correct or extend our account of the changes they have made. Clearly this method does not produce singular techniques or manuals of procedure for community building. Instead, it offers multiple ways to conceive action. (For complementary, but different, reading of the lessons in some of these same stories see Mount, 1991; O'Brien & Lyle-O'Brien, 1993; O'Brien and Lyle O'Brien, 1992).

The changes we have learned from include: establishing adequate support for family life; moving from an institution, medical hospital, nursing home, or group residence into one's own home; moving from one's family's home to a home of

one's own; getting a job in an ordinary community workplace; and attending primary, secondary, or tertiary school as a member of ordinary classes. Because all of the people we learned from have substantial disabilities, these changes have each required negotiating entry into new settings and new roles, usually as the first person with a substantial disability to do so; arranging adequate systems of personal assistance; acquiring appropriate technical aids and devices; and finding adequate funding.

These important personal changes have additional significance because none of them resulted from the routine operation of the human service programs available to the people involved. While people who work in services often play an important role in these stories og change, their contributions lie well outside their job descriptions and often challenge their employer's expectations. While money allocated for services usually contributes to making or sustaining the change, people have always had to work to change the established use of these funds, and sometimes have had to create new agencies, or even new policies and laws to make the change they seek.

Of course, these are not the only possible stories of community building. Some service agencies, and a few authorities responsible for service systems, have invested in learning how to routinely offer assistance in ways that build community. But the changes we want to learn from here take service system resources into a different social space, a social space created around and with a particular person, and among people who discover new commitments and new ways to act through their shared effort. This context reshapes the usual functions and processes of service in ways which yield creative responses to common problems and important lessons for service reformers.

A brief sketch of a story of positive change provides a basis for a description of five types of person to person commitments, which people involved in community building have found useful in understanding and extending their efforts.

"There's a delicacy about her..."

This phrase, "There's a delicacy about her", captures an aspect of Lisa which was not apparent to the people who lived and worked with her during the years that she moved from one residential facility to another and another and another . In those settings, her inabilities, primarily her inability to use words, and her challenging behaviors defined her person and her life. She was moved from place to

place as one service agency after another concluded that she was too difficult to serve. Through these hard years, Lisa's mother, Gemma, remained a fierce advocate for appropriate services, providing Lisa with a firm anchor in a turbulent and threatening world. (This sketch of Lisa's story is drawn from Joyce, 1993.)

As Lisa faced yet another transfer to the "Behavioural Ward" of an institution, a setting which had proven dangerous to Lisa in the past, Gemma and Lisa found a committed assistant in John, an official in the regional bureaucracy that oversees services to people with disabilities. John decided that he wanted to respond to the political pressure around Lisa by developing individualized services for her. With Gemma's consent, John assigned Marilyn to design and develop services for Lisa. In the ensuing eight years Marilyn has proven herself as one of Lisa's strongest allies, though her job and family circumstances have changed several times.

Marilyn approached Lisa and Gemma with the image of a social structure in mind, an image transmitted from the experience of Judith Snow and her circle of friends as they developed individual supports for Judith (Pearpoint, 1990). She says, "Once I would have asked, '**What** can I bring to Lisa?' But, instead, I asked, '**Who** can I bring to Lisa.' ...I introduced the idea to Gemma by saying that I thought we needed more people..." (p.3, emphasis in original).

Gemma consented, but she remembers, "[Marilyn] described a circle where Lisa would have people around her who'd care. I didn't think it would ever happen. I though she was asking too much of herself and others. At first I was rather skeptical; I didn't think people would come through with their commitments. I didn't believe a support circle could happen -but it has!" (p.4).

The support circle hasn't just happened. It developed initially from Marilyn's invitations to people she knew. Then, as action with and around Lisa grew, some people brought in others, like Elinore (the first person Marilyn invited) who involved her husband, Charlie, and then her daughter Lynne, who later became a key paid assistant to Lisa. As Marilyn continued to act outside Gemma's expectations of a service worker, the circle grew stronger. Gemma says, "...I began to trust Marilyn because I saw her as a leader -she's determined and what she sets out to do she does. It's amazing to me that she brought in her friends." (5).

Since its beginning, the circle has offered Lisa's brothers, Michael and Antosh, a specific focus for their desire to anchor their sister's future. The circle's early work was difficult, especially because no service providers were willing to offer individualized supports, even though Lisa had access to substantial amounts of funding. Michael says, "...The meetings were long, and there were lots of

frustrations... A lot of the professionals were willing to listen and give advice, but few were willing to get their hands dirty or commit fully." (p. 6). Antosh identifies the continuing concern of those closest to Lisa, "I was afraid the circle would break down, that it would be too much of a burden." (6).

Dealing over time with the complexities of developing and maintaining good assistance for Lisa, as well as the challenge of understanding and clarifying Lisa's interests and capacities and finding opportuntites for her, has been challenging. So, the circle's growth has not been smooth nor has its membership been stable. When an agency agreed to organize services for Lisa, many circle members assumed that the problem was solved and became less active. At one point, only three people were regularly involved.

However, as continuing problems clarified the fact that individualized services for Lisa posed too big a challenge to the culture of the only existing agency willing to serve her, the circle regenerated and enlarged. Members of Lisa's circle joined with several families whose dreams and desires outstripped the service system's capacity. They formed an association which has created a service agency called New Frontiers, whose mission is to assist a small number people with substantial disabilities as they build their local community.

After eight years 28 people identify themselves as members of Lisa's circle. Some were introduced to Lisa by other circle members. Some initially met Lisa when they were hired to work for her as assistants (though many of Lisa's assistants have not identified themselves as members of the circle). Some have come to her through the shared work of creating New Frontiers.

Circle members do much more than have planning meetings, and some members rarely attend the meetings that do occur. But each member identifies her or himself with Lisa and with the circle, each shares some mutually interesting activities with Lisa, and all have shown their willingness to act together to protect Lisa and promote a positive future for her. Lisa benefits from the many different ways in which people have come to know her, even though these differences have sometimes caused conflicts among circle members.

The circle benefits each of its members, though it holds Lisa at its center. The circle manifests social concern to reshape its member's community; it is not an expression of pity for disability. All members can identify benefits from membership, including: discovering new skills, making friends, overcoming stereotypes, joining in enjoyable social activities, gaining confidence in ability to problem solve, finding opportunities to act vigorously on what seems right,

finding support in personal hard times, and creating confirmation of hope that people can work together to make a real difference.

With the support of the circle and the assistance of New Frontiers, Lisa's life in her home is gradually becoming more stable overall, though some of her behavioral challenges persist, and she remains unable to use words to communicate. Lisa explores the places and activities available in her city. She regularly volunteers her time to Meals on Wheels and to a local community centre. She particularly enjoys many of the meals and parties that embody the life of the circle. Through the shared work that builds and sustains the circle, she and her mother have gained many allies concerned for her future. One of them, Jennifer, says, "It's one thing to think about how far Lisa has come -I think more about where Lisa can go." (p. 34).

Herb, a psychologist who has visited Lisa and encouraged her circle, says, "...whenever I have been to Lisa's home or talked to the people who are in her circle, I have been struck by how much they love her and one another. Not in the everything-is-beautiful kind of way that has a hard time with conflict, but in the enduring, patient, and respectful way we all need, to get to the next and better version of ourselves." (20).

Five commitments that build community

As we have come to understand it, community building happens when people step outside the roles prescribed by the formal and informal administrative structures and the assumptions that typically organize life for people with substantial disabilities. Distinctions between staff and clients and family members and ordinary citizens dissolve as the familiar patterns of interaction that maintain them shift, and people discover new possibilities for shared action. This dissolution of administratively fundamental distinctions can be confusing and threatening, especially when people continue to fill administratively prescribed roles.

This confusion shows up in many ways, for example in debates about whether or not paid staff can be friends and advocates for people with substantial disabilities. Many who say yes seem to think that staff can presume that their clients will see them as friends and advocates, despite fundamental inequalities in power, and professional norms that dictate objectivity and detachment. Some, who have glimpsed the bureaucratic machinery beneath the mask of professionalized caring, say no, paid people can't be friends. Neither those who say yes nor those who say no seem to have adequate terms to describe the relationships that have developed

between Lisa and Gemma and some paid staff people. Finding new terms outside the usual administrative vocabulary allows people to discuss some of the distinctions that emerge when people work together to make change. New words offer one way to help people make sense of this different way of acting.

Community building is an intentional move into a new space; if Marilyn had chosen to focus on what services to give Lisa rather than on who to bring into her life, the support circle would not exist. Far more an improvisation in response to changing circumstances than a carefully choreographed routine, community building needs ways of identifying the kinds of actions that can make positive differences to people's shared future. Invitation lies at the heart of community building and shapes the responses people offer. Searching for ways to communicate the different kinds of contributions that people can make to one another offers those who make invitations a vocabulary for considering their options.

As we have considered the differences between stories, like Lisa's, that include positive changes and stories that do not, as yet, include much change, we have labeled five different person to person commitments, which are identified on the figure below. In stories of change, we can usually identify people enacting these different commitments. In stories where no change has occurred, the absence of people making one or more of these commitments is notable. This does not mean that no change can happen without each commitment, only that significant change will require even more effort in the absence of one or more of them. When we describe these commitments to people who appear to display them, the people involved usually accept the description as more or less accurate for them, though they sometimes say that the words we have chosen seem a bit strange. So these descriptions have heuristic rather than predictive or technical value.

The notion of commitment involves accepting a particular kind of responsibility by acting on it. One person can share more than one commitment with a person with a substantial disability. Commitment implies freedom; the roles assigned to people by administrative structures do not contain, nor can they compel, any of these commitments. Someone may be both a paid staff person and an ally, as Marilyn has been for Lisa. But John, as Marilyn's boss, can not assign her to be Lisa's ally, though John could, as a person Marilyn respects because of his willingness to take personal risks on Lisa's behalf, invite and encourage her to consider alliance. Commitments are not disability specific; they seem necessary in any effort to build community. People with disabilities can, of course, enact any of the commitments, just as people without disabilities can. These commitments are a matter of one's heart's desire, not of status.

People who commit to **anchor** another person love that person and are concerned with that person's well being over time. They share their life with the person and act as a source of continuity for the person through the ups and downs of life; they have custody of important memories. They stand with the person in difficult times. They act vigorously to protect the person from harm. They seek ways to reconcile with the person when the person has offended them or when they have fallen out with the person. They want to continually grow in knowledge of the person, and especially of the person's gifts and capacities, even though this may be difficult when it challenges habitual patterns of expectation. They work to identify and create opportunities for the person. The other person figures in their decision's about their lives; when facing an important choice they

will not need to be reminded of their importance to the person. They actively assist the person to expand relationships with others who may come to care.

People's family members may be anchors, as Gemma is for Lisa. But some family members can be overwhelmed by their own circumstances or by fear or by stereotyped thinking and be unable to anchor their son or daughter or brother or sister or spouse in making the kind of change that builds community. Unrelated people -including paid staff- can find themselves loving a person with a substantial disability in this way, though this can be confusing and difficult for others to understand and can creat significant conflicts for the staff person who is an anchor.

People who commit themselves to be **allies** share their time and resources with the person to make a jointly meaningful change. They offer practical help, assist with scheming and problem solving, lend experience and skills, and offer useful information. They make contacts for one another and bring others into the alliance. They usually enjoy the person's company in some mutual interest, and they often like to share food and drink. Because allies know the person in distinct ways, they come to have important knowledge of the person's interests and capacities. On the basis of this information, and their knowledge of community opportunities, they can join the person and the person's anchors to define a future worth working towards. Allies may be linked more closely to the person than they are to one another. If a shared project calls on them to work together, allies may have to deal with their differences with one another and be willing to negotiate conflicts instead of just walking away.

A person's allies may choose to consciously form a circle, as Lisa's have, or their relationship may be more like separate spokes related to the person, with no rim linking them together. Because many people with substantial disabilities have been isolated and separated by prejudiced treatment, it may be necessary to purposely invite people to consider forming alliances with them around an important change, as Marilyn did when she formed a circle around developing individualized supports for Lisa.

Assistance provides the help a person requires to deal with the effects of disability so that they contribute their gifts to the change effort. Service managers offer assistance, as John did for Lisa, when they allocate funds with the flexibility to allow involved people design and re-design a system of everyday personal assistance. Personal assistants provide necessary help with daily activities, from eating and dressing and housework to working and participating in community activities. Professional assistants offer specialized help to deal with difficulties in

movement or communication, or learning, or problem solving, or dealing with problematic behaviors or feelings.

The particular commitment of assistance is to offer necessary help, in a respectful, creative, and flexible way, without taking over the persons life. The art is to assist without intruding between the person and other people or activities the person wants to be involved with. The gift of assistance is to resonate with and thus to amplify the person's bodily and mental contributions to the change effort.

Assistants can, of course, become deeply involved with the people they help: many of Lisa's allies have worked for her. But the commitment to the paradox of assisting without intruding or controlling remains a unique contribution, and it is important that assistants be clear when it is time for them to make it. (Adler, 1993).

Some people with substantial disabilities rely primarily on family members for the help they need, particularly their mothers and sisters. When publicly funded assistance fails to provide alternatives to care by family members, the person's relationship with caregivers can become deeply constraining for them all. When necessary assistance is only available in settings that segregate and control people, opportunities to make the kind of changes that build community are very limited.

Associations are the social structures groups of people create to further their interests. They may be structured formally or informally. They may be focused on social change or on their members' protection or enjoyment or personal development or other political objectives. They may be organized around the particular interests of people with disabilities, as New Frontiers is, or they may be organized around other community purposes, as the community centre where Lisa volunteers is. People with substantial disabilities have typically been excluded from the benefits and responsibilities of association membership, so a great deal of untapped energy can become available if a person's allies can facilitate their membership in associations that can share and shape the person's interests (see Kretzmann and McKnight, 1993).

Agendas organize political action to insure just and effective public policies and their proper implementation. People with substantial disabilities and their families and allies have often joined political coalitions to work for such changes as: personal assistance services and family support services under the control of users or people close to them; inclusive schooling; necessary assistance for individual employment; safe, accessible, and affordable housing; safe, convenient, and accessible transportation; access to adaptive technology and devices; and adequate

cash income without stigma. The coalitions and actions that form around agendas multiply the influence of people and their circles.

People who share these five commitments and nurture them over time are likely to create new ways to build and be a community. Lisa and the support circle around her work slowly and modestly to increase the capacity of people in her city to deal creatively with diversity, to decide justly when prejudice threatens participation in the benefits and responsibilitiues of citizenship, and to make good use of the public funds appropriated to the service of people with disabilities. Lisa and her allies have contributed direction and hard work to the creation of an innovative agency to assist them in defining and making their contribution to common life. They have claimed a new space for shared action, and thereby expanded possibilities for themselves and for other people with substantial disabilities.

The importance of community building

Community building matters importantly to people who claim the freedom to define and pursue a desirable future in a society whose economic sector threatens to colonize the whole of life. Community building matters particularly to people with substantial disabilities because the modern economy typically assigns them to either be objects of professional work or to be on waiting lists to demonstrate the need for such work. Because this work is bureaucratically organized, people with substantial disabilities are vulnerable to domination by state administrative mechanisms when they receive the services politically intended to relieve their kin from the unpaid work of caring for them. When it is not simply invisible, their economic marginalization and administrative domination is often celebrated as desirable, because people with substantial disabilities are widely perceived as less than fully human and cast into devaluing social roles as objects of pity or charity or menace or dread.

When people with substantial disabilities and their friends work together to build community, they can open a social space in which marginalized people can join people who are insiders to penetrate delusions about disability and uncover shared meaning through joint projects. Within this social space, people whose lives may be dominated by professional definitions of disability can find some relief, and even occasional liberation, from the burdens of full time clienthood. Within this social space, people can unfold the human capacity for confirmation of one another as each is, and as each can become.

Judith Snow (1990), whose emancipation from a chronic care facility occurred through her shared life and work with a circle of support, reflected on the contribution outsiders (who she terms "outcasts" below) can make to community building simply from bringing the experience of being an outsider to ordinary people ("the ordinaries", as she calls them).

> The gift of surviving and growing through change belongs to the outcast... Living on the edge of chaos changes the people who survive it. You become very aware of the value of things ordinary citizens take for granted; things like having your opinion listened to, having a chance to make a mistake, to be forgiven and to have a chance to try again; things like having friends and family who celebrate holidays with you and who will tell their friends that you are looking for a job. Living on the margin either burns you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; someone who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions. But how can this really be, especially since these dreamers still have the characteristics that marked them as outcasts in the first place? They will still lack good judgment, or find it hard to learn to read, or be disabled. Solving this problem is critical, for otherwise the outcasts and the ordinaries are very good at maintaining an invisible wall between their two worlds. (pp. 126-127)

She goes on to say that this invisible wall can only be breached by long term willingness to build new kinds of relationships between those who are reaching out and those who are reaching in. In the five commitments, we have tried to describe the terms of those new relationships.

Tensions in community building

A sort of discomfort surrounds these new relationships and some of the social structures that invite and support them. The very term, community building, reflects the tensions that give rise to this discomfort, and to some frank disagreements. For some people, community does not seem to be something that can be built : community is, spontaneously, or it is not. To speak of building community violates what can, and should, only develop naturally and opens the

door to a kind of clumsy, intrusive, and embarrassing social engineering, likely packaged in warm and fuzzy psycho-babble. For others, community isn't worth building because it represents a failed structure for human development, incapable of dealing constructively with human diversity or addressing injustice. To speak of building community distracts from the necessity of living as successful individuals in a cosmopolitan and impersonal society. For still others, whether it is desirable or undesirable, the very possibility of community is gone. On their view, the turbulent forces that fragment our times replace community with cleverly marketed counterfeits, like "Community Care," which masks impersonal rationing by joining two words with high appeal, emptying them of content, and filling the hollowed out space with bureaucratic professional activity. To speak of building community is to be guilty of a kind of naive and dangerous flashback to the 1960's or the 1780's.

Awareness of each of these disagreements and discomforts clarifies the work of community building. The economic and administrative forces that shape so much of modern life make it necessary to undertake conscious efforts to claim common spaces and to build within them. And conscious efforts can be and feel halting, tentative, uncertain, and uncomfortable. Recognizing and honoring human diversity and enriching joint action with differing gifts presents so large a challenge that no one who sets out to build community will get far before encountering its threats and frustrations. Efforts to build community that overcome the invisible walls between outsiders and ordinaries must be modest in scale and in expectation.

This kind of building is nothing like the massive imposition of individual will on masses of people through architectural technology which Ayn Rand characterizes in *The Fountainhead*. It is much more like the kind of building celebrated by Bernard Rudofsky (1964) in *Architecture without Architects*. As Rudofsky beautifully illustrates, this kind of building is vernacular rather than formal; commonly practiced by inhabitants rather than sketched and controlled by professional experts who will not live within the results; rooted in a particular landscape rather than imposed upon it; purposely created for human comfort rather than scaled for mass consumption; and built in stages as use and resources expand rather than master planned and financed at high cost. He notes two inspiring qualities of successful vernacular builders: they work to make oases of public spaces, and, "they do not hesitate to seek out the most complicated configurations in the landscape [often choosing] veritable eyries for their building sites..." (p.4).

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